An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

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Subcommittee on Emergency Communications, Preparedness, and Response

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U.S. House of Representatives

"Caring for Special Needs during Disasters: What's Being Done for Vulnerable Populations?"

Tuesday, June 15, 2010 311 Cannon House Office Building 10:00 A.M. Ms. Chairwoman, and Members of the House Homeland Security Subcommittee on Emergency Communications, Preparedness, and Response:

Introduction

Thank you for the opportunity to submit for the record this written testimony about the critical importance of ensuring that our emergency management infrastructures meaningfully afford all Americans, including Americans with disabilities, an opportunity to be prepared for and survive emergencies, and to resume and rebuild productive lives after them.

This is my first occasion to provide congressional testimony as Chairman of the National Council on Disability. Accordingly, by way of introduction, I would like to provide some personal background. I broke my neck in during a wrestling match as a senior at Walt Whitman High School in Bethesda in 1986. Initially paralyzed from the neck down, I was fortunate that my spinal cord was compressed and bruised but not severed, enabling a partial recovery from paralysis. Like many people who acquire disabilities later in life, my initial impulse was to disassociate from disability. I viewed disability as debilitating, and my injury as an enemy. I was only vaguely aware of the Americans with Disabilities Act in 1990, and it did not occur to me then that it had anything to do with me. I had broken my neck in a wrestling match and had a pronounced limp. But I did not view myself as a "person with a disability" nor as part of a "disability community."

I would not be here today absent the extraordinary impact of the National Council on Disability on my life. I refer not to my current role as Chairman but rather the opportunity afforded me in 1996 to write a history of the Americans with Disabilities Act on a contract through what was then the National Rehabilitation Hospital Research Center. At the time I was a Ph.D. student in American history at the University of North Carolina at Chapel Hill writing a dissertation about the slavery debates, and I had recently endured a difficult bout of depression related to my injury. In fact, I had reached a point where I did not think I would ever be able to hold a meaningful job. Depression can cast long shadows.

Writing about the history of the ADA transformed my personal and professional identity. As I interviewed dozens of leaders in the disability community I was riveted by the power of their story and the gravity of the change wrought through the ADA. I began to view disability as a source of power and pride rather than debilitating stigma. With NCD's 1997 publication of *Equality of Opportunity: The Making of the Americans with Disabilities Act*, I became a person with a disability, and part of the disability community.

I also became employable. My opportunity to write about the ADA's history for NCD restored the confidence in myself that I had lost in the darkness of depression. As a direct result of my NCD ADA history project, I was nominated for and later became Associate Director for Disability Outreach in the White House Office of Public Liaison in 1998 and served through the end of the Clinton Administration. Thereafter I completed my Ph.D. with a dissertation on the disability rights movement in 2002 and went on to

obtain my J.D. from Yale Law School in 2005. I also got married and am the proud father of three beautiful daughters, ages 3, 5, and 7.

Serving as NCD Chairman thus completes a circle for me. NCD was my gateway to the disability community. It is thus a profound and humbling honor to serve as Chairman of this important agency.

My remarks today reflect several years of important work led by the National Council on Disability and documented in a series of reports beginning in April 2005 with the pre-Katrina report, *Saving Lives: Including People with Disabilities in Emergency Planning*, and two reports in the aftermath of Hurricane Katrina. NCD's leadership in highlighting the importance of people with disabilities in emergency response and preparedness had a direct impact on the provisions of the 2006 Homeland Security Appropriations bill's Post-Katrina Emergency Management Reform Act (PKEMRA). Among other things, PKEMRA required FEMA to create and hire a National Disability Coordinator and to interact, consult, and coordinate with NCD on a list of activities. Congress's FY 2007 appropriations enabled NCD to undertake and complete its most recent report on the subject, the 2009 *Effective Emergency Management: Making Improvements for Communities and People with Disabilities* report.

These reports, which have helped to create awareness of the breadth of concerns facing people with disabilities during all phases of a disaster, have played an important role. Of course, reports alone are not enough. What is critical is taking these reports' findings and drilling down into the day-to-day decision making and relationship building required to effect the change that these reports have indicated is so direly needed. We should never find ourselves exchanging business cards for the first time at the moment of a disaster. When that happens, people become statistics instead of stories of successfully saved lives. Consider the tragic story of Benilda Caixeta. She was on the phone with Marcie Roth during Hurricane Katrina and pleading for transportation from her home. Benilda reported that water was gushing in shortly before the phone died. Five days later her body was recovered floating next to her wheelchair. Each of the cold casualty statistics represents the loss of a lifetime of potential to contribute to our country's well-being. We can, and must, do better.

Today, there are three main points I would like to make:

- 1) First, it is time to focus on implementation. It is time to move beyond identification and deliberation of issues and recommendations, and beyond dense reports that state and restate problems. We must shift our focus to active implementation of evidence-based successful practices in areas of known need. NCD is committed to joining our federal partners, including Congress and FEMA, in shifting focus toward implementation and determining how to allocate scarce resources to meet a plethora of acute challenges.
- 2) **Second, we must insist on integrated emergency planning**. We cannot divide emergency planning into two distinct frameworks one for "general"

preparedness and one for "special needs" preparedness. This division is particularly problematic when, as now, it results in devoting a miniscule portion of overall resources to "special needs" that are too often disproportionately more costly and resource intensive. Being well-prepared for emergencies means addressing <u>ALL</u> peoples' diverse needs, including the needs of people with disabilities, in a single, integrated, and unified approach to emergency preparedness. Vastly more important than a "Special Needs Plan" is the meaningful inclusion of people with diverse disabilities in every phase of disaster management planning, in all communities. Emergency preparedness planning must be informed at every juncture by the experiences and inputs of people with disabilities.

3) Third, we need to collaborate across silos to build accessible infrastructures. So long as we continue to work in agency silos, state and federal silos, individuals and nonprofits and government silos, and congressional committee silos, our progress will be halting and scattered. We need to think creatively about how to replicate exemplary and successful collaborations and continue to insist upon working across silos to effect positive change for people with disabilities.

In addition to the amplification of these points that follows, attached to this testimony is a summary document of key recommendations and findings from our *Effective Emergency Management* report germane to this hearing, which is meant to supplement my testimony. (See attachment).

It is Time to Focus on Implementation.

I am proud of the extraordinary role NCD has played prior to my tenure as Chairman in drawing attention to the needs of people with disabilities in emergency planning. As an independent agency charged with making recommendations to the President and to Congress, our work on emergency management is a prime example of NCD's critical role in helping to ensure that we hold true to our nation's disability policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency.

To date, NCD is probably best known for its substantive and lengthy reports, including its reports on emergency management. While NCD will continue to develop reports when warranted or requested by Congress and the President, I am persuaded that NCD has reached a critical juncture that requires us to focus less on generating high-level recommendations encased in lengthy prose and focus more on rapid and responsive advice and guidance about effective implementation. This conclusion is informed substantially by comments I have received from congressional staff and other key federal stakeholders. Accordingly, NCD is currently undertaking a strategic planning process in coordination with the U.S. Office of Personnel Management to determine how best to equip NCD to fulfill a new and more actively-engaged role in helping to implement critical recommendations about disability policies and programs.

This shift in NCD's emphasis forms a backdrop for my testimony today. At this point, there is little mystery about the scope of actions needed to ensure that people with disabilities are not the first to be sacrificed when disaster strikes. We have enumerated, justified, and detailed our recommendations in several reports. Of course, we all agree that we need to implement solutions rather than crystallize with increasing clarity the scope of the problem. It is now time for us to support active implementation of these recommended actions in areas of known need.

With regard to emergency preparedness, NCD is prepared, and has in fact begun, to make this transition toward implementation of recommended actions. One example is a need identified by the Government Accountability Office (GAO) to improve the coordination and collaboration between NCD and FEMA. I am pleased to report to this Subcommittee that FEMA Administrator Fugate and I had an excellent first meeting on April 23, 2010. I am also pleased to report that Marcie Roth, Director of FEMA's new Office of Disability Integration and Coordination, and I enjoy a strong working relationship rooted in our collaborations in various contexts over the past 12 years. Administrator Fugate has suggested that he and I meet regularly until we can point to tangible signs of progress. Toward that end, I have charged NCD Vice Chair Fernando Torres-Gil with a lead responsibility for the Council and plan to have him join me in meeting with Administrator Fugate whenever possible. Dr. Torres-Gil brings a wealth of emergency preparedness experience and will be an extraordinary asset as NCD and FEMA deepen our collaboration.

As Assistant Secretary for Aging during the Clinton administration, Dr. Torres-Gil worked closely in assisting elderly and disabled persons to recover from the Midwest floods of 1993 and the Northridge earthquake of 1994. He directed the aging network of area and state units on aging to give particular attention to the needs of older adults with disabilities. As a current board member of The California Endowment and the Los Angeles Airport Commission, he continues to advocate for people with disabilities and older adults and is helping to bridge the communication gaps between disability and aging communities whose needs clearly overlap, even if both groups have a tendency to disassociate from one another for fear of the stigma of being viewed as "old" or "disabled."

Historically, our work on emergency management has come in the form of Council oversight of outside contractors producing reports for NCD. This type of reporting has played an important role in the past, and we have targeted our lump-sum emergency management appropriation for financing contract research. However, if one agrees that most of the issue identification has been accomplished and one concurs with the general scope of NCD's prior recommendations, I would contend that NCD's greatest value in the years ahead will come from a more resource-intensive process of being far more directly engaged with decision-makers in actualizing the recommendations.

Dr. Torres-Gil and I pledge our commitment and that of the Council to aggressive implementation of our emergency management recommendations and look forward to

providing this Subcommittee with an update on our progress in the future. One of the obvious challenges is how best to allocate our agency's limited financial and human resources. NCD has a \$3.2 million annual lump sum appropriation (along with a one-time, \$300,000 appropriation for emergency preparedness) to support a mission of advising the President and Congress on the entire sweep of disability programs and policies, including every type of disability and every conceivable disability issue. At present, nine full-time staff supports the work of a 15-member, Presidentially-appointed, and Senate confirmed part-time Council. Most Council members, including myself, balance their service on NCD with full-time careers. We embrace the breadth of our mission even as we acknowledge that difficult choices must be made about priorities.

As I mentioned previously, NCD is undergoing a strategic planning process to optimize our allocation of resources, and as the Chairman of the Council, I am committed to including emergency management activities as a discreet item in our strategic planning process. We welcome an opportunity to strategize with our congressional partners about how best to marshal the resources necessary to fulfill Congress' charge to NCD. I will turn now to discussing two of the highest priority areas in need of aggressive implementation.

We Must Insist on Integrated Preparedness Planning.

Winston Churchill once said, "However beautiful the strategy, you should occasionally look at the results." I respectfully urge this Subcommittee to apply the sentiment behind that quote to its work involving "caring for special needs." Reference to the unique considerations of people with disabilities in disasters is often termed "special needs." While some people would certainly prefer the label of "people with special needs" over "people with disabilities," NCD embraces the view of the disability advocacy community that "special needs" connotes separateness and tends to reinforce debilitating stigma. People with disabilities are people first, and if we truly believe that disability is a natural part of the human experience, labeling the work done to address its implications for emergency planning should not be referred to as "special."

As people with disabilities, we may have various physical, sensory, and/or psychiatric limitations, but our needs and wants are fundamentally the same as all other Americans— to live, to learn, and to earn. Furthermore, while recognizing that many people with disabilities are uniquely vulnerable in times of emergency and disaster, we need to focus greater energy on empowering people with disabilities to act responsibly and appropriately at such times, rather than default with the suggestion that they should wait to receive care. Although identifying and focusing on "caring for special needs" is no doubt well-intentioned, such a focus can have the unintentional, deleterious impact of segregating, isolating, and thereby failing to address adequately the actual needs of people with disabilities.

People with disabilities have long been marginalized by the emergency management community. Instructions relating to the unique needs of people with disabilities have typically been limited to a few lines in an emergency plan, if they are mentioned at all.

"Disabilities" have generally been placed into one large category, often labeled "special needs," without genuine consideration for the unique circumstances of different disabilities. Emergency planners have often decided what people with disabilities need without consulting them. This practice further alienates people with disabilities and increases their vulnerability during disasters.

I often say that there is no such thing as "disability policy." Rather, when we say "disability policy," we are actually simply thinking about all policies through a lens of consideration of its impact on people with disabilities. This perspective is no less relevant in emergency planning. We cannot divide emergency planning into distinct frameworks for "general" preparedness and "special needs" preparedness. What we need to do is ensure that all aspects of emergency preparedness planning always integrate and fully incorporate the unique life experiences of people with disabilities. This goes for responses to disasters, as well.

Given the diversity of disability experiences and the highly variable progress toward accessibility in communities across the country, the most effective way to ensure that the needs of people with disabilities are taken into account during emergencies and disasters is to have people with disabilities be an integral part of the planning process from start to finish – equal partners. President Eisenhower once said, "Planning is essential; plans are worthless." I am grateful to FEMA Administrator Fugate for calling my attention to this idea. It has helped give shape to my vision for the future of NCD and is certainly a central principle in understanding how NCD views effective emergency preparedness for people with disabilities.

Many of NCD's prior recommendations get to the heart of this need for participation in the planning process. NCD has, for instance, recommended that there be a network of regional coordinators across the country. My good friend Marcie Roth is doing an extraordinary job as Director of FEMA's Office of Disability Integration and Coordination. However, despite my highest confidence in her abilities and dedication to these issues, I am deeply concerned about her ability as one individual to shoulder the enormous task laid before her. I am heartened to be confident, based on my ongoing dialogue with Administrator Fugate, that he understands these weighty concerns, like few people outside the disability community. I believe Administrator Fugate, Ms. Roth, and I all agree that an important indicator of success will be when all people engaged in emergency management work have disability toward the center of their radar screens rather than expecting that the concerns of people with disabilities are the job of only a few individuals—whatever their rank may be.

Regional Coordinators Could Create Crucial Linkages

PKEMRA established the National Disability Coordinator position at FEMA, which marked a critical step in institutionalizing staff positions representing disability interests. Despite encouraging work seen to date from the national coordinator (a position that is, regrettably, currently unfilled), the frequency and geographic dispersion of disasters annually underscores that regional replication of the national coordinator position is

vital. Regional coordinators similar to the national coordinator's position, set up in each regional FEMA office, could enhance the effectiveness of the national coordinator by drilling down on local disability issues to more aggressively and timely respond to the needs of people with disabilities. Regional coordinators could liaise between voluntary agency liaisons and voluntary organizations that function in the National Response Framework, as well as oversee disability task forces. Such actions would go a long way in shoring up communication linkages between local disability communities and emergency managers.

Meaningful involvement of people with disabilities in emergency management planning must happen across the country, not just here in Washington between NCD and FEMA. Success will be marked by the education of and enhanced awareness among all stakeholders in the business of emergency management—which is to say, albeit in varying ways, each and every American. And we have a long way to go.

People with Disabilities are Routinely Excluded from Preparedness Activities

People with disabilities are routinely excluded from preparedness exercises, drills, and other planning processes. As noted in one study of 30 disaster sites, only 27 percent of emergency managers had completed available training on disabilities, and fully 66 percent of the counties had "no intention of modifying their guidelines to accommodate the needs of persons with mobility impairments" because of problems stemming from costs, the availability of staff, awareness, etc.² This lack of involvement in disaster planning also compromises emergency planners' credibility to people with disabilities when hazard and preparedness information is disseminated. The likeliest solution a partnership approach to planning that brings disability organizations, with which people with disabilities may already be familiar, to the table with emergency planners.

One-Size-Fits-All Approaches Do Not Work

People with disabilities are often grouped together as a homogenous unit when considering preparedness provisions, which does not adequately account for the range of differences that exist between disabilities or the accompanying range of issues for which emergency managers must prepare to successfully respond to this diverse population. Generic, one-size-fits-all approaches to disaster planning do not work. Each type of disability presents its own unique set of barriers during disasters. For example, people with hearing disabilities may not receive weather warnings that broadcast only over audible technologies, whereas the most urgent concern of people with mobility disabilities may be negotiating the stairs of a fire escape during evacuation. Addressing barriers created by the unique needs of people with disabilities can serve to better protect all people during times of disaster. Children, seniors, and people with disabilities all benefit from an expanded set of options to support those at risk during an event.

People with Disabilities as Active Participants in Preparedness Planning

People with disabilities must be involved in emergency planning for several reasons:

- First, their knowledge of potential barriers is invaluable. People with disabilities make excellent consultants or advisors during emergency plan development;³
- Second, their personal experience in overcoming these barriers adds tremendous validity to plan solutions; and
- Third, the empowerment experienced through participation may prompt people with disabilities to take preemptive actions and encourage others to follow suit.⁴

Invited participants must be representative of all types of disabilities. Equal representation is imperative, as each disability can present unique challenges to consider during emergency plan development. For example, people with only mobility disabilities can receive warnings via ordinary technology, but they may not be able to self-evacuate; whereas people with hearing disabilities may be able to self-evacuate, if they are properly notified. Advocacy groups that work for and with people with disabilities should also receive an invitation to the planning table. The collective knowledge gained by including these individuals and organizations is invaluable to plan development. In addition, the individuals or groups responsible for implementing the plan, such as first responders, should also be involved in the process. The insight gained through working side by side with people with disabilities during the plan development process will enhance everyone's understanding of the plan's purpose.

We Need to Collaborate Across Silos to Build Accessible Infrastructures

We need to think creatively about how to work across silos, including congressional committee jurisdiction. If our communities' housing, communications, transportation and related infrastructures are not accessible now, our response to emergencies will be impaired from the start. Therefore, even though housing, communications, and transportation may not fall within a single committee's jurisdiction, all the committees who do have distinct jurisdiction over those topics will only achieve shared overarching objectives if they coordinate efforts. While we mourn the tragic loss of life and destruction of buildings in the wake of major disasters, built in the tragedy is the opportunity to improve lives by rebuilding our society more inclusively. We can only do this if we collaborate and coordinate across all varieties of silos.

Problems Posed by the Built Environment

As I mentioned briefly before, historically, society has viewed disability through a medical model, which explains disability as one's personal, biologically-understood limitation, rather than through a socio-political model, which views disability as a consequence of faulty assumptions within the broader social, economic, and political environments. (The landmark civil rights law, the Americans with Disabilities Act (ADA), was written and is premised on the latter model.) Relying on the medical model to understand disability has had the consequence of deemphasizing examination of the built environment and social responsibility to create a safe setting for everyone. One research team remarked, "Traditional perspectives, based on assumptions of individual limitation, have shaped the construction of disabled people's vulnerability to natural hazards as tragic yet unavoidable." This is simply untrue. However, by ignoring the

built environment, people with disabilities are further alienated and the safety of everyone who responds to an emergency or disaster is jeopardized. Contributing to concerns is the fact that "the most accessible entrances tend to be the best route out of the building for everyone; nondisabled people head there first in an emergency, thus clogging those exits intended for the disabled, who have no alternative exits." Researchers in this area emphasize the need to construct the built environment to be accessible to everyone, rather than relying upon people with disabilities to understand and act on detailed instructions in an environment that is not supportive of their functional needs.

When evacuation is necessary, additional attention must be directed toward the availability of adequate transportation for individuals with disabilities and the technology or mobility devices on which they rely. According to the Survey of Hurricane Katrina Evacuees, the most common reason provided by respondents for not evacuating was "I did not have a car or a way to leave." In studying the aftermath of Hurricane Katrina among New Orleans residents, GAO found that state and local governments did not "integrate transportation-disadvantaged populations" into their evacuation plans. GAO also found that most state officials did not believe that many of their residents needed transportation assistance, despite U.S. Census data to the contrary. Further emphasizing the importance of this consideration, the recent Citizen Corps 2009 survey showed that over half of the respondents reported needing help with transportation out of their area in the case of an emergency (55%). 11

When considering individuals with disabilities who lack transportation, emergency planners must plan for the evacuation of assistive devices and service animals, as well. Assistive devices are often custom-fit for the individual and should be evacuated with him or her to ensure maximum independence, lower reliance on emergency assets, and speed post-event recovery. Service animals are also vitally important to their owners' ability to maintain independence and should be evacuated with the person.

Housing Concerns

Perhaps surprisingly, housing is one of the least examined areas of recovery research, despite its importance. Lower income housing tends to take a disproportionate hit during a disaster because it is likely to be older and less likely to be up to code; located in a floodplain or other hazardous area; and less structurally able to withstand an event (such as manufactured housing). Thus, seniors and people with disabilities at lower incomes presumably bear a higher risk of displacement from their homes.

Public housing can be problematic when it has been affected, particularly locations that are approved through the Section 8 Housing Choice Voucher Program. Although HUD maintains lists of available units across the nation, those units may not be located nearby. In past disasters, HUD and local housing authorities have identified and verified appropriate locations for replacement rentals. After the California wildfires in 2007, HUD established a new National Housing Locator System. The system invited prospective landlords and property owners to list units. Approximately 26,000 units were identified

within a 300-mile radius of San Diego County. The list included the ability to search for accessible units, although additional concerns remained, including proximity to work, family, health care, banking, pharmacies, and other routinely accessed sources of support.

In New Orleans, public housing units remain unavailable while they are being rebuilt by HUD and area housing authorities. Concern has been expressed by local residents that the new units, which will be in mixed-income ranges, will displace or deter lower income residents. Finding housing near vital support systems needed by people with disabilities, the elderly, and people with medical conditions is also of concern. For example, relocation 100 miles away from a familiar senior center or dialysis center will be problematic.

After Hurricane Katrina, FEMA failed to provide temporary trailers that were accessible. In *Brou v. FEMA* (the Department of Homeland Security was also named in the suit), successful plaintiffs argued in a class action discrimination suit that the federal agency had not provided accessible trailers (e.g., with wheelchair ramps, maneuvering room, or grab bars), resulting in a longer wait for temporary housing. As another example, housing advocates have noted in conference presentations that mitigation elevations along the Gulf Coast displace people with mobility disabilities and senior citizens. Some organizations report that some of these people have been forced to choose congregate care over independent living. *Brou v. FEMA* was one of several efforts by the disability community that have resulted in changes at FEMA when it comes to disaster response and recovery. In another example, FEMA is incorporating disability-specific ideas and language into its National Disaster Housing Strategy and Plan.

Conclusion

Marking meaningful progress in addressing the needs of people with disabilities in times of disaster requires implementation – follow-through – on identified solutions. It requires deliberate and thorough preparations that must include input in all disaster phase planning from people with disabilities. As self-advocating experts, people with disabilities offer invaluable knowledge of existing and potential barriers as well as creative and personal experience in overcoming them. Further, inclusion of people with disabilities throughout emergency phase planning promotes personal preemptive actions and enhances the credibility of emergency management personnel in times of actual emergency. Finally, marking meaningful progress requires working across silos and thinking holistically about peoples' lives – zooming out from action steps to ensure the solution integrates across systems in a sensible way.

Disability is a normal part of the human experience. Anyone at anytime can acquire a disability—as I did during a high school wrestling match. And acquiring a disability can just as well open the door to new opportunities as present new challenges—as I eventually discovered. Furthermore, there is considerable overlap in the challenges faced by persons with disabilities, seniors, and residents of low-income households in disaster-threat situations. People with disabilities should thus not be viewed as one

more special interest group that drains resources from the common pool. Rather, planning for and accommodating people with disabilities often means being better equipped to serve all people.

On behalf of the Members of NCD, thank you again for the opportunity to contribute this testimony to the written record. As we are just over a month away from the 20th anniversary of the ADA, we very much look forward to working in collaboration with this Subcommittee on closing the emergency planning gaps that remain.

www.gao.gov/new.items/d06790t.pdf.

¹ National Council on Disability, Emergency Management and People with Disabilities: Hill Briefing, (November10, 2005), http://www.ncd.gov/newsroom/publications/2005/transcript_emergencymgt.htm (last visited June 10, 2010).

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⁵ May, P. J. (1985). Recovering from catastrophes: Federal disaster relief policy and politics. Westport, CT: Greenwood Press, 95.

⁶ Tierney, K., Petak, W., & Harlan, H. (1988). Disabled persons and earthquake hazards. Los Angeles:

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⁹ Kaiser Family Foundation. (2005). Survey of Hurricane Katrina evacuees. Washington Post, Kaiser Family Foundation, Harvard University, p. 6. Retrieved from www.kff.org/newsmedia/upload/7401.pdf. Government Accountability Office (GAO). (2006a). Preliminary observations on the evacuation of vulnerable populations due to hurricanes and other disasters. Retrieved March 3, 2008, from

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